

Congenital Heart Disease Network South Wales and South West Network Board Meeting

Date: Thursday 28 September 2017, 10:00 – 12:30

Venue: Taunton Rugby Football Club, Hyde Park, Hyde Lane, Taunton, TA2 8BU

Chair: David Mabin

Minutes

Item	Notes and Actions
1.	<p><u>Welcome, Introductions & Apologies</u> (see appendix). DM welcomed and introduced the attendees and noted apologies.</p>
2.	<p><u>Approval of Minutes</u></p> <p>The minutes of the Network Board meeting on 13 June 2017 were agreed as an accurate reflection of the meeting.</p>
3.	<p><u>Actions</u></p> <p>The actions log was updated as appended. Notable comments:</p> <p><u>Action number 1 – Yeovil and Network Pathways</u></p> <p><u>Action number 11 – Use of Skype/Videoconferencing for joint calls between patients</u></p> <p>AT confirmed that the Truro team has accessed the JCCs remotely on several occasions and SP agreed that this had worked well. The new equipment has been tested with Cardiff and functioned well.</p> <p>AT confirmed that up to 8 colleagues are able to join in the JCCs remotely simultaneously. There are funds and the network team needs to establish a roll-out plan for remote access to the JCCs for all the centres.</p> <p><u>ACTION – AT to establish a roll-out plan for access to the JCC videoconference facilities</u></p> <p><u>Action number 16 – Consultant Job Planning Requirements</u></p> <p>CM explained that a letter had been sent by AT to each centre, asking clinical directors / service managers to confirm if the job planning requirements of the NHS standards were being met. CM requested any clinician who has not received a job planning letter to let the network team know and they will send the letter again. CM confirmed that JD had surveyed consultants’ intentions in terms of workforce issues and the results of this survey would be discussed under Item 8 of the agenda (Network risks).</p> <p><u>ACTION – CLOSED.</u></p> <p><u>Action number 21 – Website</u></p> <p>CM said that the time-scale for the launch of the website has slipped as a result of delays caused by the procurement process.</p> <p><u>Action number 28 – Access to UHW Systems through Cardiobase</u></p>

AT confirmed that this has not yet been achieved, but it is an issue he is looking at closely and wants to improve.

ACTION update – AT – to draft guideline (with assistance of DW) outlining how clinicians gain access to UHW Systems through Cardiobase.

Action number 35 – Paediatric protocols

There was discussion as to these protocols and what is required to develop them for the region.

DM and SP noted that there is a need to align the protocols between UHB/UHW.

SP said that there is a need for clinicians from the Level 3 centres to work closely with Michael Yeong and Demetris Taliotis to produce the protocols.

AT reiterated that there are protocols in each centre which all need to be standardised.

ACTION update: SV to continue to work with Michael Yeong and Demetris Taliotis around what progress has been made with the protocols and to contact the Welsh Paediatric Cardiology Network for their input/collaboration.

Action number 43 – Review of the UHB Surgical Capacity Plan

This action was discussed on item 7 of the Agenda.

Action number 44 – Identification of Opportunities for Improved PIC Transfers between UHB and UHW

DW confirmed that there had been a couple of recent cases of patients being transferred from UHB to UHW due to a lack of capacity at UHB.

Action number 46 – Pregnancy and Obstetric Care Protocols

SC confirmed that she will check that the protocols have been agreed at UHB Trust level (departmental, divisional governance and then onto the Document Management System). She will then send them to HW for her to review if they are in line with Welsh practice. SC will then circulate these protocols to the Network to be adopted.

Action number 47 – Development of a Patient Folder with Key Information

CM confirmed that this will be developed as part of the Network Website.

Action number 49 – Welsh Standards

CC's written report explained that the likely timeframe for the Welsh review of standards would take place after the NHS England consultation has closed in July 2017.

CM explained that CC has now left and that she will progress this with his replacement once in post.

Action number 50 – Specialist Nursing Provision

	<p>Nursing provision remains a challenge across the region with inequitable link nurse provision.</p> <p>It was proposed that the following actions be taken:</p> <ul style="list-style-type: none"> - Link nurse role description be identified (duties, education, support/training) - Learning to be shared from those centres that have begun to establish the roles (e.g. how it was funded / approved, practicalities, benefits / value-add to 'sell' the role) - The network team should support individual centres in progressing business cases for investment in link nurses <p>ACTION - SV to lead the above actions</p> <p><u>Action number 51 – UHB Surgical Capacity Plan</u></p> <p>It was confirmed that JD had supported the UHB paediatric team in developing a capacity plan for the surgical waiting list and this</p> <p>ACTION - CLOSED.</p> <p><u>Action number 52 – Fetal Out of Hours Rota</u></p> <p>AT confirmed that he had asked colleagues for an expression or interest in being on an out of hours rota and noted that he was awaiting further responses.</p>
4.	Items Arising
	<p><u>For discussion and feedback: Annual Report and Newsletter</u></p> <p>AT checked if those present had received a copy of the Annual Report. He explained that there was not as much engagement in developing the content as the Network team would have liked, due to the tight deadline requested by UHB to produce the report. There was general approval from the attendees of the report.</p> <p>CM sought the views and comments of the Board members as to the Newsletter and confirmed that it can be accessed online. The link is as follows:-</p> <p>http://www.uhbristol.nhs.uk/media/2891942/newsletter - mar_17.pdf</p> <p><u>WATCh update</u></p> <p>Will Marriage, Paediatric Intensivist and Lead of WATCh¹, introduced himself and made a presentation to the Board.</p> <p>Following the presentation there was a discussion about the illustrative case which formed part of the presentation regarding the policy of “automatic acceptance”.</p> <p>The presentation was well received by the Board who expressed a general vote of confidence in the service that WATCh provides.</p>

¹ Wales and West Acute Transport for Children

5.	Level 3 Centres Update
	<p>DM presented this update to the Board, referring to the paper ‘Level 3 Centres – Exception report narrative’.</p> <p>DM drew the Board’s attention to one of the main risks in the Network which is the issue of clinicians retiring or moving on and not being replaced quickly enough. For example, the PEC in Torbay has moved on and it will take 6/9 months for a replacement to be in post.</p> <p>DM made particular reference to the issue raised by Torbay adults team around the challenges faced when attempting to track patient’s journeys at the Level 1 Centre.</p> <p>There followed a general discussion about the delay in clinicians in Level 3 centres struggling to get access to surgical discharge summaries.</p> <p>ACTION – CM to carry out a brief survey around access to discharge summaries and surgical operational notes around the network.</p>
6.	Level 2 Centre Update
	<p>DW provided the following update to the Board:-</p> <p>Key Updates (Progress against key work areas, best practice to share, local education events)</p> <ul style="list-style-type: none"> • Local job planning process nearing completion • Financial approval to recruit into 5th consultant post • CNS back to full complement following return from maternity leave and a recruitment • VC resource room has been refitted • Exploration of database links to Welsh Clinical Portal (letter, report and ECG export to centralised Welsh EPR) • Funding approval to purchase new echo machine for NNU (replacing a 16 year old machine) • Plans in place to deliver 3 fetal sessions per week – leave periods not fully covered, however <p>Risks / Concerns to Escalate to Network</p> <ul style="list-style-type: none"> • Fetal referrals from ABHB
7.	Level 1 Centre Updates
	<p>Bristol Royal Hospital for Children</p> <p>AT updated the Board as follows:-</p> <ul style="list-style-type: none"> • The fetal consultant locum post was not appointed to. There will be a gap until the fetal consultant starts in Sept 2018 after maternity leave. • Catherine Armstrong has been recruited as a locum. She is not able to do fetal work, but will help with the paediatric clinics. • The waiting times for both follow-up and new outpatients are still too long. • The surgical waiting list is a bit too long, but there has been an improvement in numbers. PICU

	<p>is operating less than the number of beds due to nurse shortages.</p> <p>ACTION – CM to request a report from PICU about capacity issues and plans</p> <p><u>Bristol Heart Institute</u></p> <p>SC provided the Level 1 update for the BHI by way of presentation – see attachment.</p>
8.	Network Update
	<p>CM, SV and AT updated the Board on the Network team’s activities which was summarised as follows: (Slides also attached).</p> <p><u>Summary of self-assessment and visits</u> – CM confirmed that the Team had visited all but 3 of the Level 3 centres. The key challenges highlighted by the exercise are transition, nursing support, image-sharing and psychology. She confirmed that the analysis of the RAG ratings is an ongoing and active piece of work. DM indicated that an average would be useful to have a baseline comparison of the centres in the South West and South Wales. CM asked the members of the Board to email her with their thoughts on what information would be useful to Centres following the completion of the visits, and confirmed that the Team will contact each centre with a summary of the visit, actions agreed, their self-assessment and bench marking information.</p> <p><u>Website</u> – CM confirmed that the Team will get the website launched as soon as possible, following delays due to the procurement process.</p> <p><u>Board- meeting feedback</u> – CM confirmed that the Network Team had noted and acted upon feedback following the survey conducted by JD after the last Board meeting.</p> <p><u>Network Risks</u> – CM outlined the current Network risks.</p> <p>ACTION – CM to add PICU capacity at BRHC and no PEC in place in Torbay to the risk register.</p> <p><u>Patient Engagement (Cardiff adults)</u> – SV outlined that she will be focusing on the ACHD event being held in Cardiff in the Autumn with the support of BS and SF and the preparation for the launch of the website.</p> <p><u>National context</u> – AT confirmed the following:-</p> <ul style="list-style-type: none"> • NHS England Consultation now closed • Decisions awaited at NHS Board level September 2017 • CRG meeting October <p><u>Education – PEC day, other forthcoming events</u> - SV confirmed that there will be a PECs Training day on 8/2/18, a Paediatric Cardiac Study day on 17/11/17 and that the British Congenital Cardiac Association Annual Conference will take place on 9th and 10th November.</p>
9.	Dashboard/Exception Reports from Units
	<p>CM presented the Network dashboard and summary of exception reports for September 2017 (see report for full details. N.B. The Report presented was correct as at Tuesday 26 September but an updated version will be circulated with the minutes to include data provided after the requested</p>

	<p>deadline prior to Board).</p> <p>CM brought the Board's attention to the following - for adult's services, only half of the centres had responded. Capacity was a concern in outpatients, with up to 52 week waits being incurred in some places. In Children's services, again only around half of centres had responded. There were high numbers of overdue outpatient follow-ups in Bristol, although the surgical waiting list had decreased. Despite this, concerns remained as we head towards winter pressures/capacity pressures on PICU. CM also noted long waiting times in Taunton.</p>
10.	Commissioner Update
	<p>A commissioner update was provided to the Board by way of paper prior to the meeting as CC, RW and VL had sent apologies.</p> <p>CM confirmed that CC has left his post at WHSSC and that she will make contact with his replacement as soon as he/she is in post.</p>
11.	Patient/Support Group/ Charity Update
	<p>NM brought to the attention of the Board two issues which have been raised with the Network team by RT:-</p> <p>First, concerns that sometimes clinical letters contain content and terminology that can shock patients/families, as it was felt that these things were not discussed or understood at the time of the discussion. This has been an issue raised several times via the Facebook support group.</p> <p>Secondly, concerns around how parents in challenging situations can access support out of hours. Parents do not know where to turn to at difficult times.</p> <p>There was discussion about how parents should seek psychological support, particularly at the weekends and out of hours.</p> <p>DM suggested that parents should be encouraged to contact their cardiologist or CNS team about psychological support.</p> <p>ACTION – CM to contact Vanessa Garratt to find out what support is available for parents from adult/paediatric psychologists, especially at weekends and in the evenings.</p>
12.	Any Other Business
	<p>The next meeting is Tuesday 19 December 2017, 10:00 – 16:00 at Reed Hall in Exeter.</p> <p>NM outlined the BHF request for the Network team support in sharing a survey for parents of children with heart conditions. (Link is: https://r1.dotmailer-surveys.com/3d2fkd7e-5f2l4y82)</p> <p>ACTION – RB to share link for BHF survey with the Network.</p> <p>The Network Team are seeking a Network Governance Lead and CM asked the members of the Board to contact her if they or other colleagues are interested.</p> <p>DW confirmed that the CNS team in UHW will arrange for a patient story to be presented at the next Board meeting on 19 December.</p>

Attendees

Ashtekar, Sandeep	SA	Consultant Paediatrician, Aneurin Bevan UHB (via VC)
Benefield, Rachel	RMB	Administrator – CHD Network Team
Blakemore, Catherine	CB	Consultant Cardiologist, Torbay and South Devon NHS Foundation Trust
Cathy Carey	CC	Consultant Cardiologist, Torbay and South Devon NHS Foundation Trust
Clinchant, Andre	AC	Lead Nurse and Paediatric Oncology Outreach Nurse, Children's Community Nursing Service, Taunton & Somerset NHS Foundation Trust
Curtis, Stephanie	SC	Consultant Cardiologist and ACHD lead, University Hospitals of Bristol NHS Foundation Trust
Elbehery, Soha	SE	Consultant Paediatrician, Aneurin Bevan UHB (Nevil Hall)
Elmasry, Ola	OE	PEC, Royal Cornwall Hospital NHS Trust, Truro
Finch, Sarah	SF	ACHD CNS, University Hospital of Wales, Cardiff (via VC)
Gage, Susie	SG	Paediatric Cardiology and Surgical Pharmacist, University Hospitals of Bristol NHS Foundation Trust
Gandhi, Manish	MG	Consultant Cardiologist, Royal Devon & Exeter NHS Foundation Trust
Lambert, Rebecca	RL	Staff Nurse (ACHD) Clinic, Taunton & Somerset NHS Foundation Trust
Liversedge, Helen	HL	Associate Specialist Obstetric and Gynaecological Ultrasound, Royal Devon & Exeter NHS Foundation Trust
Mabin, David	DM	Chair of CHD Network and PEC, Royal Devon & Exeter NHS Foundation Trust
Maddicks, Hilary	HM	PEC, Royal United Hospitals Bath NHS Foundation Trust
Moss (nee Marnell), Caitlin	CM	Manager – CHD Network Team
Marriage, Will	WM	Paediatric Intensivist and Lead, WATCH
Morris, Nicola	NM	Parent/Support Group, Heart Families South West
Nash, Becky	RN	Patient Representative
Osborne, Nigel	NO	PEC, Royal Devon and Exeter Foundation Trust
Padmanabhan, Sam	SP	PECSIG, Royal Cornwall Hospital NHS Trust, Truro
Shiers, Bethan	BS	ACHD CNS, University Hospital of Wales, Cardiff (via VC)
Thompson, Ellaine	ET	Clinical Service Manager, Taunton & Somerset NHS Foundation Trust
Tometzki, Andrew	AT	Clinical Director – CHD Network Team and Consultant Paediatrician, University Hospitals of Bristol NHS Foundation Trust
Vernon, Sheena	SV	Lead Nurse - CHD Network Team
Wallis, Helen	HW	Consultant cardiologist, ACHD and Specialist pregnancy care, ABM ULHB
Wilson, Dirk	DW	Consultant Paediatric Consultant, University Hospital of Wales, Cardiff (via VC)

Apologies

Name	Inits.	Job Title
Amiri, Hussein	HA	Patient Representative
Baulch, Mary	MB	Matron/Children's Lead, Royal Cornwall Hospital NHS Trust, Truro
Bedair, Radwa	RB	Consultant Cardiologist, University Hospitals of Bristol NHS Foundation Trust
Bowen, Samantha	SB	Technical Head of Echocardiography, University Hospital of Wales, Cardiff
Coslett, Christopher	CC	Specialised Services Planning Manager Cwm Taf LHB - Welsh Health Specialised Services Committee
Edwards, Francis	FE	Paediatric Palliative Care Clinical Nurse Specialist, University Hospitals of Bristol NHS Foundation Trust
Gilbert, Melanie	MG	Matron, Child Health and NNU, Royal Cornwall Hospital NHS Trust, Truro
Hawker, Corrina	CH	Patient Representative
Holman, Jennifer	JH	PEC, Gloucestershire Hospitals NHS Foundation Trust, Gloucester
Lewis, Sian	SL	Managing Director, Cwm Taf LHB - Welsh Health Specialised Services Committee
Lewis, Vaughan	VL	Clinical Director, Specialised Commissioning NHS South, NHS England
Mashford, Kevin	KM	Patient Representative
Osborne, Nigel	NO	PEC, Royal Devon and Exeter Foundation Trust
Packer, Liza	LP	Patient Representative
Parry, Andrew	AP	Consultant Paediatric Surgeon, University Hospitals of Bristol NHS Foundation Trust
Parker, Sally	SP	Heart Families South West
Skipwith, Gina	GS	Women's and Children's Operational Manager, Torbay and South Devon NHS Foundation Trust
Stuart, Graham	AGS	Consultant Cardiologist, University Hospitals of Bristol NHS Foundation Trust
Tidcombe, Rachel	RT	Patient Representative
Tulloch, Rob	RMT	Consultant Cardiologist, University Hospitals of Bristol NHS Foundation Trust
Walsh, Rod	RW	Senior Service Specialist, NHS England
Waters, Noelle	NW	Assistant Service Manager, Aneurin Bevan UHB